

Progress through Partnership: The NINDS 2014 Nonprofit Forum
Lister Hill Auditorium/Natcher Conference Center
National Institutes of Health, Bethesda, MD
September 23-24, 2014

Day 1: Lister Hill Auditorium

8:30-9:00 a.m.	Registration <i>Atrium</i>
9:00-9:15 a.m.	NINDS Director's Welcome Story Landis, NINDS Director <i>Auditorium</i>
9:15-10:30 a.m.	When is the Time for Handoff? How to Engage the Pharmaceutical Industry in Your Disease <i>Panelists:</i> Rajesh Ranganathan, NINDS, <i>Chair</i> Cristina Csimma, Cydan Development Susan Dickinson, the Association for Frontotemporal Degeneration Sharon Hesterlee, Parent Project Muscular Dystrophy Cartier Esham, Emerging Companies, Biotechnology Industry Organization
10:30-10:45 a.m.	Break
10:45 a.m.-Noon	Nonprofit Success Stories <i>Panelists:</i> Paul Gross, Hydrocephalus Association, <i>Chair</i> Pat Furlong, Parent Project Muscular Dystrophy Lauren Stiles, Dysautonomia International Ron Bartek, Friedreich's Ataxia Research Alliance (FARA)
Noon-1:30 p.m.	Lunch
1:30-2:30 p.m.	How Can Patients Work with CTSAs? <i>Panelists:</i> Walter Koroshetz, NINDS Deputy Director, <i>Chair</i> Meryl Sufian, NCATS Ron Bartek, FARA Lisa Guay-Woodford, Children's National Health System
2:30-3:30 p.m.	Clinical Outcomes <i>Panelists:</i> Kurt Fischbeck, NINDS, <i>Chair</i> Thomas Crawford, Johns Hopkins Jane Paulsen, University of Iowa Walter Koroshetz, NINDS

3:30-3:45 p.m.	Break
3:45-5:00 p.m.	The Power of Partnerships: Engaging Patients in PCORI Research <i>Panelists:</i> Sarita Wahba, Patient-Centered Outcomes Research Institute, <i>Chair</i> Megan O'Boyle, Phelan McDermid Foundation Janice Buelow, Epilepsy Foundation
5:00-6:00 p.m.	Reception <i>Atrium</i>

Day 2: Natcher Conference Center

8:00-8:30 a.m.	BRAIN Initiative (Plenary) Story Landis, NINDS Director <i>Room E1/E2</i>
9:00-10:00 a.m.	Concurrent Breakout Sessions Breakout 1 (Room E1/E2): How Can We Help You and How You Can Help Us? Vicky Whittemore, NINDS, <i>Moderator</i> Breakout 2 (Room F1/F2): How do You Build Your Research Program? Amelie Gubitz, NINDS, <i>Moderator</i>
10:00-11:30 a.m.	Meet the Program Directors <i>All rooms (TBA)</i>
11:30-11:45 a.m.	Break
11:45 a.m.-1:00 p.m.	NPO Special Session: NIH from the Nonprofit Perspective Paul Gross, Hydrocephalus Association, and Cynthia Rothblum-Oviatt, A-T Children's Project, <i>Moderators</i>
11:15 a.m.-12:00 p.m.	Nuts and Bolts: Building and Sustaining an Innovative Research Ecosystem
12:00 p.m.-12:30 p.m.	Pitfalls and Speed Bumps on the Road to "Success Stories"
12:30 p.m.-1:00 p.m.	Advocacy: Update and Perspectives from Research!America